



NTSAD
national tay-sachs
& allied diseases association

39th annual family conference



**march 30
to april 2, 2017**

**dallas/addison marriott
quorum by the galleria**

**14901 dallas parkway
dallas, texas 75254**

**register online
at www.NTSAD.org**



why go to the conference?

“Attending the conference helped us know **we weren't alone**. That there were other families facing the same challenges that we were, and how to handle them and get what we needed for our child. We gained a new family, and learned quite a bit of information we did not know. We are so **grateful for all the people with NTSAD** and what we have gained.”

...Eli's mom

“At our first conference I was so happy to meet the people I had gotten to know {online}, had laughed with, had cried with and had received advice from. **It felt like home**. We stayed late every night, trading stories and holding each other's children. Now every year I come. I come to get that tidbit that improves Isaac's care. Even as an "old timer", I'm always learning! I come to share my knowledge base. **I come to feel normal. I come to hug my family**. It's one thing to send virtual hugs, quite another to embrace in person!”

...Isaac's mom

“Attending the conference even after a Bela's passing **allows me to provide the same support** that was offered to me at the time I needed it the most. Even though my daughter's physical life has ended here on earth, her legacy continues to shine bright.”

...Bela's mom

session program overview

thursday

We'll be kicking off the weekend Thursday morning with our Welcome Sessions. This will be a place for everyone to meet and greet each other, as well as share their stories with the group, and learn about the program at hand and what to expect. Our Peer Support Groups, Youth Group, Navigating the System, and Helping Healthy Siblings Cope sessions will round out the afternoon before our day culminates with our welcome dinner.

friday

Find out more about the latest news in the Research Update Session. Participate in the Men's, Women's, Late Onset, or Grandparent groups, while our Youth Group goes on their first retreat. Share a moment of quiet reflection during our commemoration ceremony honoring all of our loved ones who have left us too soon, or in the palliative care choices session. With some open evening time you can check out the Dallas area or join us for our annual pizza party.

saturday

Join groups that address daily health management, living with grief, strengthening relationships while caring for a child, or while grieving, and living with Late Onset diagnoses. In the afternoon, join us to learn about how to become more actively involved with NTSAD, and what NTSAD can do to support you. The day ends with our final peer group meetings before our big Celebration Dinner in the evening!

sunday

We may come together as strangers, but we leave as family. Take a moment to give hugs, take pictures, and say "Until next year" at brunch.

camp snuggle

Our team of beloved nurses will snuggle, cuddle and adore your child so you can attend sessions. With skilled loving care, they will tend to your child's every need. This year Camp Snuggle will consist of two separate rooms: one for our affected children who need some quiet and stillness, and one for those who'd like a little more noise and activity.

camp sunshine (0-9 years)

Just like the parents, siblings are often the only one in their community with a special or angel sibling. At Camp Sunshine, siblings enjoy games, arts-n-crafts and more, all while being with other kids just like them!

youth program (10-17 years)

This year we offer an enhanced program starting on Thursday, March 30 and followed by two off-site field trips scheduled for Friday, March 31 and Saturday, April 1st for Youth Group participants. This program will encourage mentoring between the older and younger participants.

This year, siblings 18 years and older are encouraged to volunteer, attend sessions and/or participate as adults.

Our hired professional childcare providers set the industry standard for safety. All staff hired receive rigorous training and thorough background checks.

details, details, details

hotel reservations

NTSAD's room rate is \$162, with tax. Follow the link on the conference page at www.ntsad.org to make your reservation online. Call 1-800-228-9290 for NTSAD room block rate. Space is limited.

registration

Registration includes conference materials and all meals. Affected children and children under age 3 are free! It **does not** include additional fees for accommodations and transportation. Please note the conference is not a fundraiser. The fee covers the per person meal expense for the whole conference.

meals

All meals - Thursday lunch through Sunday brunch - are included in the registration fee. Meals are a special time for families to socialize and connect. It is important we know what meals you and your family plan to attend. Please indicate specific dietary needs and/or food allergies on the registration form.

helping hand grants

Funding is available to lend a 'Helping Hand' to those who need financial aid with registration and/or hotel. *No travel is covered.* We want to help as many families as possible.

Visit www.NTSAD.org for more information on how you can earn a free registration by selling Helping Hand Raffles and how to download an application for a Helping Hand Grant for you and your family.

**Attire is casual throughout the conference.
Program subject to change without notice.**

registration form

Send in no later than: March 8, 2017

NTSAD, 2001 Beacon St., Suite 204

Boston, MA 02135

fax (617) 277-0134 | diana@ntsad.org

Date Arriving _____ Date Departing _____

I/We are traveling by **CAR** or **PLANE** (please circle)

Name(s): _____

Address: _____

City: _____ State: _____ Zip Code: _____

Cell Phone: (_____) _____

Email: _____

Is this your first conference? YES / NO

REGISTRATION

Registration fee must accompany this form.

_____ Adult (\$315/weekend)

_____ Child(ren)'s meals (\$150/weekend.)
(affected children are free)

_____ I sold 63 raffle books to earn one (1) free
registration(s). Enclosed are the proceeds.

_____ I want to apply for a Helping Hand Grant.

\$ _____ **Total Registration Due** (Checks due 3/8)

(Personal Checks, Amex, MasterCard, Visa and PayPal)

Credit Card # _____ Exp. Date: ___/___

Signature on File: _____

Please complete the back as well.

CAMP SNUGGLE (Affected Children)

THURSDAY _____ YES _____ NO

FRIDAY _____ YES _____ NO

SATURDAY _____ YES _____ NO

NAME _____

DIAGNOSIS _____

DATE OF BIRTH _____

COMMENTS:

CAMP SUNSHINE (Healthy Siblings)

THURSDAY # _____ YES _____ NO

FRIDAY # _____ YES _____ NO

SATURDAY # _____ YES _____ NO

NAME(s) _____

DATE(S) OF BIRTH _____

COMMENTS:

MEAL SIGN-UP (Please indicate number eating at each meal and note any dietary requests, such as Kosher, vegetarian, or allergies.)

Thursday

Welcome Lunch # ___ Adults # ___ Kids' Meals

Welcome Dinner # ___ Adults # ___ Kids' Meals

Friday

Breakfast # ___ Adults # ___ Kids' Meals

Luncheon # ___ Adults # ___ Kids' Meals

Pizza Night # ___ Adults # ___ Kid(s)

Saturday

Breakfast # ___ Adults # ___ Kids' Meals

Awards Lunch # ___ Adults # ___ Kids' Meals

Celebration Dinner # ___ Adults # ___ Kids' Meals

Sunday

Brunch # ___ Adults # ___ Kids' Meals